

111TH CONGRESS  
1ST SESSION

# S. RES. 141

Recognizing June 2009 as the first National Hereditary Hemorrhagic Telangiectasia (HHT) month, established to increase awareness of HHT, which is a complex genetic blood vessel disorder that affects approximately 70,000 people in the United States.

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## IN THE SENATE OF THE UNITED STATES

MAY 11, 2009

Mr. JOHNSON (for himself and Mr. BENNETT) submitted the following resolution; which was referred to the Committee on Health, Education, Labor, and Pensions

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# RESOLUTION

Recognizing June 2009 as the first National Hereditary Hemorrhagic Telangiectasia (HHT) month, established to increase awareness of HHT, which is a complex genetic blood vessel disorder that affects approximately 70,000 people in the United States.

Whereas Hereditary Hemorrhagic Telangiectasia (HHT), also referred to as Osler-Weber-Rendu Syndrome, is a long-neglected national health problem that affects approximately 70,000 (1 in 5,000) people in the United States and 1,200,000 worldwide;

Whereas HHT is an autosomal dominant, uncommon complex genetic blood vessel disorder, characterized by telangiectases and artery-vein malformations that occurs

in major organs including the lungs, brain, and liver, as well as the nasal mucosa, mouth, gastrointestinal tract, and skin of the face and hands;

Whereas left untreated, HHT can result in considerable morbidity and mortality and lead to acute and chronic health problems or sudden death;

Whereas 20 percent of those with HHT, regardless of age, suffer death and disability;

Whereas due to widespread lack of knowledge of the disorder among medical professionals, approximately 90 percent of the HHT population has not yet been diagnosed and is at risk for death or disability due to sudden rupture of the blood vessels in major organs in the body;

Whereas it is estimated that 20 to 40 percent of complications and sudden death due to these “vascular time bombs” are preventable;

Whereas patients with HHT frequently receive fragmented care from practitioners who focus on 1 organ of the body, having little knowledge about involvement in other organs or the interrelation of the syndrome systemically;

Whereas HHT is associated with serious consequences if not treated early, yet the condition is amenable to early identification and diagnosis with suitable tests, and there are acceptable treatments available in already-established facilities such as the 8 HHT Treatment Centers of Excellence in the United States; and

Whereas adequate Federal funding is needed for education, outreach, and research to prevent death and disability, improve outcomes, reduce costs, and increase the quality of life for people living with HHT: Now, therefore, be it

1        *Resolved*, That the Senate—

1           (1) recognizes the need to pursue research to  
2       find better treatments, and eventually, a cure for  
3       HHT;

4           (2) recognizes and supports the HHT Founda-  
5       tion International as the only advocacy organization  
6       in the United States working to find a cure for  
7       HHT while saving the lives and improving the well-  
8       being of individuals and families affected by HHT  
9       through research, outreach, education, and support;

10          (3) supports the designation of June 2009 as  
11       National Hereditary Hemorrhagic Telangiectasia  
12       (HHT) month, to increase awareness of HHT;

13          (4) acknowledges the need to identify the ap-  
14       proximately 90 percent of the HHT population that  
15       has not yet been diagnosed and is at risk for death  
16       or disability due to sudden rupture of the blood ves-  
17       sels in major organs in the body;

18          (5) recognizes the importance of comprehensive  
19       care centers in providing complete care and treat-  
20       ment for each patient with HHT;

21          (6) recognizes that stroke, lung, and brain hem-  
22       orrhages can be prevented through early diagnosis,  
23       screening, and treatment of HHT;

24          (7) recognizes severe hemorrhages in the nose  
25       and gastrointestinal tract can be controlled through

1 intervention, and that heart failure can be managed  
2 through proper diagnosis of HHT and treatments;

3 (8) recognizes that a leading medical and aca-  
4 demic institution estimated that \$6,600,000,000 of  
5 1-time health care costs can be saved through ag-  
6 gressive management of HHT in the at-risk popu-  
7 lation; and

8 (9) encourages the people of the United States  
9 and interested groups to observe and support the  
10 month through appropriate programs and activities  
11 that promote public awareness of HHT and poten-  
12 tial treatments for it.

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